



Human Rights Committee Training Resource Manual

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Human Rights Committee Training Resource Manual

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SECTION ONE

Introduction from Self Advocates



Introduction from Self Advocates

In a survey that was completed by people with disabilities, they had the following to say about what is important to them:

- **I want to be able to do what I want on the week end.**
- **I want to choose my friends.**
- **I want to have my friends come over.**
- **I want to cook whenever I want.**
- **I want to use the microwave.**
- **I want to go out to eat at a restaurant that I choose.**
- **I want to date.**
- **I want to take a vacation.**
- **I want to spend my own money.**
- **I want to choose what I want to do in my free times.**
- **I want to take a bath whenever I want.**
- **I want a job – not a day program.**
- **I want to live in a place of my own.**
- **I want to make my own decisions.**

In short, people with disabilities want what every other person wants and they have the same rights as all other people.

SECTION TWO

Purpose of Human Rights Committees

Purpose of Human Rights Committee

People with mental retardation and other related disabilities are entitled to the same rights available to all other citizens. When a person is unable to exercise his or her rights as a citizen, society is obligated to intervene, to safeguard these rights and to act humanely and conscientiously on that person's behalf.

South Carolina Code of Law (44-26-70) relating to the rights of people receiving services from DDSN requires that each DDSN Regional Center and local DSN Board establish a Human Rights Committee.

The purpose of the manual is to provide Human Rights Committees with a solid philosophy on which to base their work as well as functional guidelines to follow to insure that service users are afforded Fundamental Fairness and Due Process when programs are purposed which may limit a person's rights and everyday freedoms.

Our Greatest Task

It is our greatest task to support the people we serve to lead complete and whole lives and to exercise their rights and responsibilities as citizens to the fullest.

SECTION THREE

Perspectives on the Historical Treatment of People with Disabilities

Perspectives on the Historical Treatment of People with Disabilities

Years	Societal Perspective	Treatment
Up to 1700s	Possessed by the devil, a sinner	Tortured, burned at stake, left to die
1800-1920s	Genetically defective; polluting the race	Hidden away
1930-1940s	Genetically defective; polluting the race	Institutionalized, sterilized, exterminated
1940-1970	Unfortunate, object of charity, pity	Institutionalized, rehabilitated
1970-2000s	Independent, self-determined	Independent; civil
1200-1700:	Accepted belief that mentally ill people (lunacy and idiocy) were possessed by the devil or evil spirits. As a result, they were routinely whipped, tortured and burned at the stake. Between 1400 and 1700 more than 100,000 women executed as witches. Many of these women had some form of mental illness or other age-related disability.	
1800:	Science begins to replace religion as the main authority guiding leaders in the West. Biology and science are used to explain the world. Instead of being seen as having a spiritual deficit, people with disabilities are seen as having a genetic deficit. People with disabilities placed under the care of medical professions, professional educators and social workers. Almshouses, workhouses, institutions proliferate in the U.S.	
1850:	Beginning of the Eugenics Movement. Goal to improve the quality of the human gene pool. People with disabilities were segregated and hidden (institutions, asylums, hospitals, segregated schools, sheltered workshops, attics) or placed on display as entertainment (freak shows, circuses).	
1861:	The American Civil War (1861-1865) – 30,000 amputations in the Union Army alone.	
1907:	Indiana became the first of 29 states to pass compulsory sterilization laws directed at people with genetic illnesses or conditions.	
1920:	German Social Darwinists feared that the degeneration of the race was due to medical care of	

	the 'weak' that had begun to destroy the natural struggle for existence. Institutionalization of people with disabilities is seen as best for them and for society. People with disabilities seen as a "drag on civilization."
1924:	The Commonwealth of Virginia passed a state law that allowed for sterilization (without consent) of individuals found to be "feebleminded, insane, depressed, mentally handicapped, epileptic and other." Alcoholics, criminals and drug addicts were also sterilized.
1930:	President Franklin Delano Roosevelt's physical disability hidden from the American public for fear that it would detract from his power and status.
1935:	The league of the Physically Handicapped is formed in New York City to protest discrimination against people with disabilities by federal relief program. The group organizes sit-ins, picket lines and demonstrations and travels to Washington D.C. to protest and meet with officials of the Roosevelt administration.
1939:	In Germany: End of Nazi sterilization program. Beginning of Euthanasia Program. 200,000 killed in total.
1945:	President Harry Truman signed a proclamation creating National Employ the Handicapped Week.
1950:	Laws still on the books in some states prohibiting persons "diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object" from appearing in public.
1961:	President Kennedy appoints a special President's Panel on Mental Retardation, to investigate the status of people with mental retardation and develop programs and reforms for its improvement.
1970:	Independent Living movement begins, grass roots effort by disabled people to acquire new rights and control over their lives.
1972:	The U.S. District Court of Alabama decided in Wyatt vs. Stickney that people in residential state schools have a constitutional right "to receive such individual treatment as (would) give them a realistic opportunity to improve his/her mental condition."

Wyatt v. Stickney

Wyatt v. Stickney, filed in the federal United States District Court for the Middle District of Alabama on October 23, 1970, was a landmark ruling that established baseline care and treatment requirements for the institutionalized mentally disabled. The suit was filed on behalf of the patients at Bryce Hospital in Tuscaloosa, with 16-year-old Ricky Wyatt as the main plaintiff. Wyatt had been incarcerated for "delinquency" but had never received any other diagnosis of mental disability or condition. The defendants in the case were the Alabama Department of Mental Health (DMH) and its commissioner, Stonewall Stickney. The suit initially was prompted by layoffs at Bryce Hospital, with attorneys alleging that insufficient staff at the hospital would prevent involuntarily committed mentally ill patients from receiving adequate treatment, a violation of their civil rights under the Fourteenth Amendment of the U.S. Constitution.

As a result of this ruling, **minimum standards** were created for care of people with mental retardation who reside in institutional care.

These minimum standards or 49 principles of care included:

- "Right to treatment"
- Establishment of the Qualified Support Professional (QSP) previously known as the Qualified Mental Retardation Professional (QMRP)
- Staff to client ratios
- Physical plant features/Dimensions
- Development of Behavior Plans
- Establishment of Human Rights Committees

SECTION FOUR

Fact Sheet: Human Rights

HUMAN RIGHTS

Q. What are human rights?

A. Typically, when people speak of exercising their rights, they are referring to those fundamental rights that are specifically guaranteed by the U. S. Constitution and each state's constitution. But, "human rights" also often refers to the basic respect and dignity that should be afforded each individual.

No one can take away a person's constitutional rights. However, Congress can add to our constitutional rights by passing federal laws. The Voting Rights Act and the Americans with Disabilities Act are examples of federal laws passed by Congress that expanded the rights of citizens. State legislators can also pass laws that expand on or explain the rights and responsibilities of citizens of their states.

Q. Do people with mental retardation have rights?

A. People with mental retardation, like all other citizens, have a vast array of protections under the law which must be recognized and protected.

Q. Have people with mental retardation always been afforded the same human rights as others?

A. There has been a long history of oppression and callous disregard for the lives of individuals with mental retardation.

This tradition, together with the societal pressure to devalue individuals with mental retardation, make it essential that those charged with their support and care be aware of the increased risks that individuals with mental retardation continue to face. They must be especially vigilant to protect the autonomy and right to equal protection under the law of individuals with mental retardation.

Q. How did the concept of human rights originate?

New concept: The idea that every human being has inherent worth and accompanying "rights" is a relatively new concept. Throughout most of recorded history, the only privileges that people had were those that were granted by the emperor or king in power. In many traditional societies, it was believed that the leader ruled by divine right and that the social order was the "will of God." The value of each person was based on his or her place in the social order. Class, race, gender or religion were considered legitimate justifications for devaluing individuals and entire segments of a society. The result for the person could be exploitation, oppression, persecution, slavery, torture or even execution.

U.S. contribution: Our own Declaration of Independence was a pivotal event in the evolution of the concept of human rights. Thomas Jefferson eloquently captured the fundamental notion of the innate right to liberty and equality with these revolutionary words: "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the Pursuit of Happiness."

Human rights internationally accepted. It was nearly two centuries later, after World War II, that the modern concept of "human rights"-that each person has inherent worth-gained worldwide acceptance. With the realization that laws had specifically authorized the unspeakable horrors perpetrated on innocent millions during World War II, the world's conscience awoke to the simple notion that some actions are wrong, no matter what. Every human being has a right to basic respect. The 1945 charter of the United Nations begins by reaffirming a "faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women"

The Universal Declaration of Human Rights: Three years later, in 1948, the General Assembly of the United Nations adopted the Universal Declaration of Human Rights. It is essentially a list of human rights. The Universal Declaration establishes uniform standards for the treatment of all persons. It proclaims that all human beings shall be entitled to:

- ⌚ equality before the law;
- ⌚ protection against arbitrary arrest;
- ⌚ the right to a fair trial;
- ⌚ freedom from ex post facto criminal law;
- ⌚ the right to own property;
- ⌚ freedom of thought, conscience, and religion;
- ⌚ freedom of opinion and expression;
- ⌚ freedom of assembly and association;
- ⌚ the right to work and to choose one's work freely;
- ⌚ the right to equal pay for equal work;
- ⌚ the right to form and join trade unions;
- ⌚ the right to rest and leisure;
- ⌚ the right to an adequate standard of living; and,
- ⌚ the right to an education

In the decades that followed the Universal Declaration, the United Nations promulgated resolutions on specific areas of concern in human rights.

In 1971, the United Nations adopted a Declaration on the Rights of Mentally Retarded Persons. A Declaration on the Rights of Disabled Persons followed in 1975.

References and Resources

Declaration of Independence

U.S. Constitution

United Nations

 Universal Declaration of Human Rights

 Declaration on the Rights of Mentally Retarded Persons

 Declaration on the Rights of Disabled Persons

Americans with Disabilities Act (Rehabilitation Act of 1973, Section 504)

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SECTION FIVE

Universal Declaration of Human Rights

Universal Declaration of Human Rights

PREAMBLE

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, Therefore THE GENERAL ASSEMBLY proclaims THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article 1.

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2.

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3.

Everyone has the right to life, liberty and security of person.

Article 4.

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5.

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6.

Everyone has the right to recognition everywhere as a person before the law.

Article 7.

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8.

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9.

No one shall be subjected to arbitrary arrest, detention or exile.

Article 10.

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11.

(1) Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.

(2) No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12.

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13.

(1) Everyone has the right to freedom of movement and residence within the borders of each state.

(2) Everyone has the right to leave any country, including his own, and to return to his country.

Article 14.

(1) Everyone has the right to seek and to enjoy in other countries asylum from persecution.

(2) This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15.

(1) Everyone has the right to a nationality.

(2) No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16.

(1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

(2) Marriage shall be entered into only with the free and full consent of the intending spouses.

(3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17.

(1) Everyone has the right to own property alone as well as in association with others.

(2) No one shall be arbitrarily deprived of his property.

Article 18.

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19.

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20.

(1) Everyone has the right to freedom of peaceful assembly and association.

(2) No one may be compelled to belong to an association.

Article 21.

(1) Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.

(2) Everyone has the right of equal access to public service in his country.

(3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22.

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23.

(1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

(2) Everyone, without any discrimination, has the right to equal pay for equal work.

(3) Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.

(4) Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24.

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25.

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26.

(1) Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

(2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

(3) Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27.

Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28.

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29.

Everyone has duties to the community in which alone the free and full development of his personality is possible.

In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30.

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

SECTION SIX

South Carolina State Law

SC state laws

SC Code 44-26 “Rights of Mental Retardation Clients”

SECTION 44-26-70 Human rights committees. [SC ST SEC 44-26-70]

(A) Human rights committees must be established for each regional center and for each county/multi-county program to:

- (1) review and advise the regional center or the county/multi-county board on the policies pertaining to clients' rights policies;
- (2) hear and make recommendations to the regional center or county/multi-county board on research proposals which involve individuals receiving services as research participants pursuant to Section 44-20-260;
- (3) review and advise the regional center or county/multi-county board on program plans for behavior management which may restrict personal freedoms or rights of clients;
- (4) advise the regional center or county/multi-county board on other matters as requested pertaining to the rights of clients.

(B) Human rights committees must be appointed by the director or his designee. Each committee consists of not less than the following five persons, except employees or former employees of the regional center or county/multi-county board must not be appointed:

- (1) a family member of a person with mental retardation or a related disability;
- (2) a client of the department, if appropriate;
- (3) a representative of the community at large with expertise or a demonstrated interest in the care and treatment of persons with mental retardation or related disabilities.

(C) The department shall establish policy and procedures for the operations of the committees.

(D) Members of the committees serve in an advisory capacity only and are exempt from liability.

SC Code 44-66 “Adult Health Care Consent Act”

SC Code 44-81 “Rights of Residents of Long Term Care Facilities”

SC Code 62-5 “Protection of Persons under Disability and Their Property”

These can be found at <http://www.scstatehouse.gov/code/statmast.htm>

SECTION SEVEN

Human and Civil Rights – Policy Statement

HUMAN AND CIVIL RIGHTS

POLICY STATEMENT

The human and civil rights of all people with mental retardation and related developmental disabilities must be honored, protected, and enforced.

ISSUE

Throughout history and continuing today, the human rights of our constituents have been limited and denied. These rights are generally recognized to include the right to life, liberty, property, access to voting, and equality of opportunity and others recognized by law. The right of people with disabilities to be free from discrimination is a basic human right that should be recognized as part of the fundamental law of the land. Advancing the human and civil rights of our constituents presents particular challenges:

- Many individuals, businesses, and other entities remain unaware of the rights of our constituents. The challenges include:
 - A history of discrimination and exclusion from meaningful participation in citizenship.
 - Societal attitudes of devaluation and fear.
 - Unfounded beliefs that they do not contribute to society.
 - Failure to provide necessary supports for full community participation.
 - Overprotection without freedom to exercise individual rights.
 - Under-compensation for labor and services.
 - Prejudice that views people with mental retardation as unworthy of public funding.

POSITION

Our constituents are entitled to human and civil rights, regardless of age, gender, race, sexual orientation, culture, severity of disability, or intensity of needed supports. These rights include life, liberty, property, access to voting, and equality of opportunity. All people with mental retardation and related developmental disabilities must have the supports they need to exercise and ensure their human rights. Local, state, and national governments must vigorously enforce all human and civil rights.

*Adopted: The Arc, Congress of Delegates, November 9, 2002
AAMR Board of Directors, May 28, 2002*

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SECTION EIGHT

What is a Rights Restriction?

What is a Rights Restriction?

"Restriction" means anything that limits or prevents an individual from freely exercising his/her rights and privileges. Something is usually considered restrictive if it impedes the enjoyment of general liberties that are available to all citizens.

**Pay attention to gut reactions and uneasy feelings.
If the proposed action makes you cringe, it is probably a
Rights restriction!!**

With any program that causes a restriction of rights, it is implied that:

- The restriction is **temporary**;
- The restriction is defined with **specific criteria** (under exactly what circumstances will it be used);
- The program is **paired with learning/training components** to assist the person in the eventual removal of the restriction;
- The restriction is **removed** upon reaching clearly defined objectives;
- **Reviewed** regularly by HRC

Material developed by Illinois DHS

SECTION NINE

Typical HRC Issues

Some Typical HRC Issues

Most commonly the formal issues presented to the HRC involve behavior plan issues. In addition, many times the issue involves use of psychotropic medication. HRC reviews the plan, focusing on current or future rights restrictions, weighing the risks/benefits of each restriction.

- ⌚ Individual rights restrictions (freedom of movement, privacy)
 - GPS tracking bracelets
 - Door/window alarms
 - Other environmental restrictions
 - One-on-one supervision
- ⌚ Restrictive behavior support plans
 - Painful/aversive treatments
- ⌚ Abuse, neglect, exploitation allegations
- ⌚ Use of psychotropic medication
- ⌚ Issues regarding informed consent
- ⌚ Guardianship issues
- ⌚ Incident report review
- ⌚ Use of Emergency procedures
 - Money management issues
 - Smoking reduction practices
- ⌚ "Do not resuscitate"(DNR) medical orders

Material developed by Illinois DHS

SECTION TEN

Guardianship

Guardianship

Guardianship is the legal transfer of some part of decision-making responsibility from an individual to a court. The court then transfers certain decision-making powers to the court-appointed guardian. The process is intended to provide someone to make decisions when the individual is deemed incompetent to make their own informed decisions. Parents are usually considered the “natural guardians” of children under the age of majority, but not of their adult children.

Guardianship is needed when a person is unable to make and communicate responsible decisions regarding his personal care or finances due to mental, physical or developmental disability.

Two basic types of guardianship are a person guardianship and estate guardianship:

1. A guardian of the person is appointed by the court when a disabled individual cannot make or communicate responsible decisions regarding his personal care. This guardian will make decisions about medical treatment, residential placement, social services and other needs.
2. The court appoints a guardian of the estate when a disabled person is unable to make or communicate responsible decisions regarding the management of his estate or finances. The guardian will, subject to court supervision, make decisions about the ward’s funds and the safeguarding of the ward’s income or other assets.

Depending on the decision-making capacity of the disabled person, the court can appoint a:

- **Limited Guardian**

Is granted the power to make only those decisions about personal care and/or personal finances that the court specifies.

- **Plenary Guardian**

Generally has the power to make all the decisions about personal care and/or finances for the disabled person.

- **Temporary Guardian**

Where the need for guardianship is decided for the period between the filing of a petition for guardianship and the conclusion of the court hearing.

Responsibilities of the Agency

- To refrain from making decisions outside the scope of guardianship

- To understand specific type of guardianship
- To support the person in making as many decisions as possible
- To assure the need for guardianship is reviewed at least annually

Responsibilities of the Guardian:

- To include the person in all decision making
- To consider the expressed desires and values of the person in all decision making

Material developed by Illinois DHS

SECTION ELEVEN

Informed Consent and Confidentiality

Informed Consent and Confidentiality

Confidentiality is an important component of a strong HRC. **Each committee member must assure that information about persons receiving services is held in the strictest confidence.** Conversations should be kept confined to the meeting room and care must be taken to assure topics are not discussed in hallways, parking lots, etc. Likewise, after meeting care must be taken that papers containing identifiable information are not left lying about.

When discussing an individual served during the meeting, organizations should use initials, identification numbers, etc. to keep complete anonymity even from the committee members. It is agreed that if discussion includes someone who is not receiving services at the agency, the person's identity must be kept confidential. With the enactment of the Health Insurance Portability and Accountability Act (HIPAA) HRCs must be diligent in assuring that their practices remain in accordance with state HIPAA regulations. Again, the intent of this statute is to assure that an individual's personal information is not shared without permission. A central aspect of the Privacy Rule is the principle of "**minimum necessary**" use and disclosure. A covered entity must make reasonable efforts to use, disclose, and request only the minimum amount of protected health information needed to accomplish the intended purpose of the use, disclosure, or request

When records are shared, or information requested, **informed consent** must be obtained.

All consents should be written in plain, easy to understand language.

SECTION TWELVE

Introduction to Due Process

Introduction to Due Process

The concept of Due Process of Law is deeply ingrained in our social and legal construct as a people, with a history going back before Magna Carta. The term “due process of law” is clearly used in the 5th and 14th amendments. Due process is meant to establish Fundamental Fairness in our proceedings when we as a society alter or restrict an individual’s right to life, liberty or property. How we proceed is found in various laws, codes and regulations and tempers the question of why and when we should proceed.

People, who have intellectual, physical, social, and related disabilities, unless otherwise determined by the court, enjoy full citizenship and are to be treated as such. When any person, group, organization or agency attempts restrict the rights of any other person or persons a strict adherence to the principles of Fundamental Fairness and Due Process is required.

It is the ultimate responsibility of the Human Rights Committee and each of its members to insure that people are supported, their rights are protected and that people are afforded due process when service providers purpose to restrict those rights. Specifically, the guiding tenet is that due process is required whenever agency actions limit individual action. This guide references Federal and State law and SCDDSN policies and procedure relating to rights of all citizens and specificity rights of persons with disabilities.

Steps to Due Process for HRC

ALWAYS ASK!

1. Has the person been invited and supported to attend the meeting?
If no, do not hear the case.
If yes, where is the person?
If not in attendance, why?
If the person chose not to attend, proceed, however, except by personal choice, not the provider, there must be a compelling reason for them not to attend.
Routine programs, staffing, transportation, other appointments, home visits, etc. are not acceptable reasons.
2. What is the reason for the case?
There must be a compelling reason/triggering events prompting the provider to purpose to restrict or limit any right or everyday personal freedoms of a service

- user. (Note: routine health care, medication, treatments and office visits absent of sedation or physical restraint do not fall into this category and need not be presented to the committee.)
3. What is the purposed intervention or action?
 4. Is this action a restriction of privacy, access, movement, association, finances, or restrictive or invasive health care etc.?
 5. What has been done before this point, alternatives, etc?
 6. What makes the intervention least restrictive?
 7. Is the intervention time limited?
 8. What will be done to actively and positively restore the person's right/remove this intervention?
 9. Has or when will staff be trained to implement this intervention?
 10. How does the intervention affect others, housemates or coworkers?
 11. Has the person given their informed consent? Yes or no?
 - A. If yes, what procedures were followed?
 - B. Was the person informed of their right to refuse?
 - C. If the person did not consent, why?
 - D. Was the person informed of their right to present their case to the committee and supported to attend the meeting?
 12. If 1 through 11 can be adequately answered and has been documented by the agency, proceed.
 13. If not, no further action is to be taken and the case is to be tabled.
 14. In all cases the committee must deliberate:
 - A. Risk vs. benefit of the restriction/intervention to the person.
 - B. If need be the person's refusal vs. less restrictive alternatives.
 - C. The actual risk to the agency vs. the obligation to protect (DDSN 510-01-DD).

(Note: the risk to the agency can not to be used as a reason not to support a person to achieve the desired outcome, i.e. not enough staff, time, etc. This point is meant to provide the committee with a way to insure that the agency has used the directive to explore the least restrictive alternative in cases involving questions of supervision of the person.)

15. The committee will decide,
 - a. to approve the proposed program/intervention
 - b. to support the person's refusal
 - c. to return the program to the agency for revision.
16. The committee chair will notify the service user and the agency head in writing of its decision.

Conduct of an HRC meeting, the basics:

1. The meeting is conducted by the committee chair or his designee not provider staff or consultants.
2. The committee is a stand alone advisory group separate from the agency. All deliberations will proceed under a principle of neutrality.
3. Committee decisions are made by vote.
4. Only committee members may vote, not provider staff or consultants.
5. Committee members whose vote may represent a conflict of interest in a case must excuse themselves from voting.
6. Staff or consultants not associated with the case in presentation are to be excused from the room. This does not apply to the ED as the Committee serves to advise the ED, however the ED may not participate in Committee deliberations except to offer information and may not vote.
7. The service user may request that any provider staff, to include the ED, not be in the room during presentation of their case and/or while they are making their refusal or appeal. The service user must be informed of this right before case presentation begins.

SECTION THIRTEEN

Some Philosophical Considerations

The Dignity of Risk

Balancing the Rights of Consumers to
Choose with the Responsibility of Agencies
to Protect

Some Philosophical Considerations

Personal Growth vs. Freedom from Harm

In general, people that live in community-based programs have greater freedom to direct many aspects of their lives. People having the freedom to make choices, freedom to fail and the chance to learn from experience.

However, it is important to make a risk/benefit analysis and determine the cost of absolute safety versus the benefit of interaction with the environment. The HRC can be a forum for this type of analysis. Many times agencies have imposed lists of restrictions in the name of safety; however, this type of thinking only fosters dependence. There are certainly situational concerns regarding the right to try and the right to fail, however, an agency cannot ignore its part in supporting this “dignity of risk”.

Risk

It is vital to remember that the adults we support are fully adults. When considering the idea of risk, we may want to ask questions such as “What supports would we put in place for ourselves or friends or family who want to do things they’ve never done before”?

- Talk about those things
- Research the best safety practices and decide if it makes sense for the current situation
- Try something for a short period of time
- Try something with someone who has more experience than we do
- Evaluate the experience and make new decisions about going forward.

Sometimes things go wrong. If they do...

- Examine what happened and think about what you’ve learned
- Don’t over-react
- Don’t write another policy that applies to everyone when something happens with one person

“Freedom is not worth having if it does not include the freedom to make mistakes.”

Mahatma Ghandi

Material developed by Illinois DHS

The Dignity of Risk

WHAT IF...

WHAT IF... you never got to make a mistake?

WHAT IF ...your money was always kept in an envelope where you couldn't get it?

WHAT IF... you were always treated like a child?

WHAT IF... the job you did was not useful?

WHAT IF... you never got to make a decision?

WHAT IF... the only risky thing you could do was act out?

WHAT IF... you couldn't go outside alone because you might run away?

WHAT IF... you took the wrong bus once and now you can't take another one?

WHAT IF... you got into trouble and were sent away and you couldn't come back
because they always remember your trouble?

WHAT IF... you worked and got paid 86 cents a week?

WHAT IF... you had to wear your winter coat when it rained because it was
All you had?

WHAT IT... you had no privacy?

WHAT IF...you could do part of the grocery shopping but you weren't allowed to do
any, because you weren't able to do all of the shopping?

WHAT IF... you spend three hours a day just waiting?

WHAT IF ... you grew old and never knew adulthood?

WHAT IF... you never got a chance?

BALANCING THE RIGHTS OF CONSUMERS TO CHOOSE WITH THE RESPONSIBILITY OF AGENCIES TO PROTECT

GUIDELINES FOR RISK MANAGEMENT

DEPARTMENT OF DISABILITIES AND SPECIAL NEEDS (DDSN)

February 1, 2002

I. PURPOSE

The purpose of these Guidelines is to give service providers a decision-making framework within which balanced and defensible judgments may be made in distinguishing between reasonable and unreasonable risks in the lives of the people they serve.

NOTE: Decisions involving “proposed health care” are governed by the Adult Health Care Consent Act and DDSN Procedural Directive 535-07-PD, “Obtaining Consent for Minors & Adults”. For purposes of that policy, decisions involving healthcare are grouped into four categories:

1. medical/ diagnostic care, studies and procedures,
2. psychotropic medication,
3. restrictive programming/ behavior support plans, and
4. admission/ placement/ discharge.

When decisions are being contemplated in these areas, those two documents take precedence over these Guidelines. However, once the substitute consent giver has been determined, concepts found in these Guidelines may be helpful to him/ her in making the healthcare decision.

II. INTRODUCTION

An important component of the DDSN Risk Management Program is associated with balancing the goal of promoting consumer independence and self-determination with the agency's responsibility to keep the individual safe from foreseeable harm. This area of risk management has taken on new importance over the last decade as a result of the shift in treatment/ habilitation that has empowered consumers to be more in control of their lives and decisions.

Exposure to risk is a part of everyday life, and it is largely through making choices and assuming some risk that judgment (i.e. capacity) is developed. However, the ability to distinguish between reasonable and unreasonable risks is sometimes a complex task, and people with disabilities can be vulnerable to abuse, neglect, exploitation and a variety of other dangerous situations that may be the result of their own decision making.

III. PROCESS OF DETERMINING DEGREE OF RISK

Finding the balance between the agency's responsibility to protect people, while at the same time promoting their personal growth and autonomy always begins with the individual and those who know him/her best. This would include the family, members of his/her "circle of support", and often the direct support professionals that work with the person on a regular basis.

A. PRESUMPTION OF FULL CAPACITY

In the eyes of the law, if a person is 18 years of age or older, and has not been adjudicated as incompetent, then there is a presumption that the person is competent to make his/her own life's decisions, and to assume the consequences of those decisions. (As mentioned above, this presumption may be restricted by the terms of the Adult Health Care Consent Act and Policy Directive 535-07-PD for decisions involving healthcare.)

B. FACTORS THAT REDUCE CAPACITY

There are certain factors that may be present in a person's life that reduce the validity of this presumption of competence. These factors generally exist with degrees of severity. Some of the factors that reduce the likelihood that a person is truly able to make all their own decisions and accept the risks involved include:

- • Level of cognitive impairment
- • Level of social adaptive impairment
- • Level of expressive and receptive language impairment
- • History and experience in decision making
- • Presence of or degree of mental illness
- • Presence of or degree of substance abuse

Using the above mitigating factors, a determination can be made as to whether the consumer has a reduced capacity to make their own decisions, and furthermore, the relative degree of the reduced capacity.

C. POTENTIAL FOR HARM

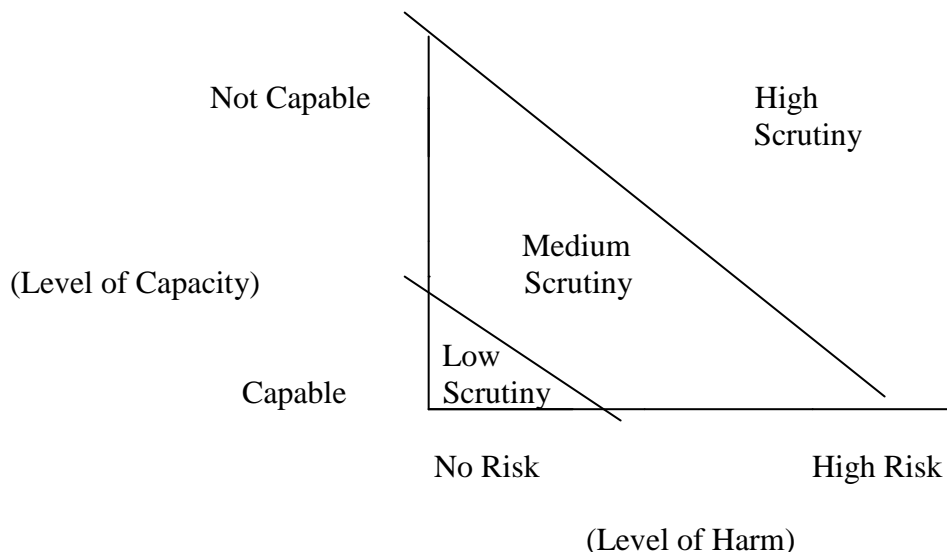
Not all decisions are of equal weight. Some decisions are of little consequence, while others may determine the quality and even the length of a person's life. The consequences of a decision, in relation to the amount of risk that is involved, may be determined by asking:

- • What is the potential that harm will occur?
- • What would be the severity of the harm?
- • What would be the duration of the harm?

Using the above answers, a determination can be made as to the degree of potential harm associated with the decision, choice or situation under consideration. The more likely that harm will result from a decision or choice, the more competence the consumer should possess before that decision is left fully in their hands.

IV. LEVEL OF SCRUTINY TO BE APPLIED

Once the person's present level of competence is determined by reviewing the factors that reduce capacity, and the level of harm that may result associated with a particular decision or situation is determined, then a simple graph can be established that may guide how much scrutiny an agency, a team (or even a family) should give to various decisions/situations. Such scrutiny should involve a careful study or examination of a situation before moving forward. This is done by plotting the level of competence on the vertical axis and the amount of risk on the horizontal axis.



A. LOW SCRUTINY (low risk combined with high capacity) would indicate that the person can make these decisions by themselves.

B. MEDIUM SCRUTINY (medium risk and/or medium capacity) would indicate that the decision or situation requires support for the person, such as consultation with the family, circle of support, treatment team, etc. before the decision is made.

C. HIGH SCRUTINY (high risk and/or low capacity) would indicate that the decision should be made by the agency, or some other substitute decision maker, after consultation with the individual, family, team, professional staff, or employing other specialty consultations.

The keys to establishing the proper balance between the individual's right to make his/her own decisions and the agency's duty to protect from foreseeable harm or risk are in:

- a) **a) having a rational basis for establishing any reduced capacity;**
- b) **b) having a rational basis for establishing any potential for harm; and then**
- c) **c) varying the degree of assistance/ support given to the consumer based upon these first two factors.**

V. REDUCING RISKS TO THE CONSUMER

Just like the rest of us, good judgment can increase with training, experience, and consultation with others. The following strategies can be utilized in order to increase the consumer's capacity to make good decisions, and by so doing, reduce the risk of harm to the individual.

- • Additional training
- • Additional experience through practice or approximating
- • Family support/ involvement
- • Professional counseling
- • Mentoring
- • "Circle of Support" involvement
- • Neighborhood support
- • Staff supervision/ shadowing/ fading of supports
- • Dividing a task/ situation into those parts that may be done independently, and those parts where supervision/ support is presently needed.

VI. REDUCING RISKS TO THE AGENCY

Service and support providers need to assure that they are on firm ground from an ethical and a liability point of view, as they turn more and more control for decision making over to the consumer. If harm does occur to an individual under the agency's care and supervision, then the agency will need to document the steps that it took in order to properly balance the rights of a person to make their own decisions with the duty of the agency to protect from foreseeable harm. Below are listed some of the steps an agency can take to accomplish this.

- • Utilize a rational, defensible process in assessing when a decision can be left in the hands of the consumer and when graduated supports should be applied.
- • Seek family involvement in decisions.
- • Use a team approach in deliberations.
- • Seek outside consultations, a second opinion, or an "independent clinical review".
- • Utilize the services of an ethicist or Ethics Committee when appropriate.
- • Communicate with other agencies or DDSN central office to determine what the standard of care has been in that particular area.
- • Document deliberations and actions.
- • Refer very difficult cases to the courts for adjudication.
- • Provide regular training to staff on making balanced decisions in this area.
- • When in doubt, err on the side of health and safety.
- • Assure that appropriate liability insurance is in place.

VII. ADDITIONAL RESOURCES AVAILABLE

Massey, P & Thompson, S; 1995, "Assisting People with Disabilities in Making Safe Decisions"; Distributed by AAMR, Washington, D.C.

Sundram, C.J., 1994. Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities, New York State Commission of Quality of Care for the Mentally Disabled, Albany, NY.

Irwin Siegel Agency, Inc. "Great Expectations: Providing Choice- Minimizing Risk"

"Risk Management System"; Massachusetts Department of Mental Retardation, December 1998; Gerald Morrissey, Commissioner

"Code of Ethics", 2000, National Alliance of Direct Support Professionals; Institute on Community Integration, University of Minnesota

Allen, Shea & Associates, "Risks & Opportunities", excerpted from Patterns of Supported Living, A Resource Catalogue; Napa, CA, June 1993

"Obtaining Consent For Minors & Adults"; SCDDSN Policy Directive 535-07-PD

“Adult Health Care Consent Act” (AHCCA); S.C. Code Ann. Sec. 44-26-60 and 44-66-30

SECTION FOURTEEN

People First Language

People First Language

Generally in choosing words about people with disabilities, the guiding principle is to refer to the person first, not the disability. In place of saying “the disabled,” it is preferable to say “people with disabilities.” This way the emphasis is placed on the person, not the disability. Disability should not be the primary, defining characteristic of an individual, but merely one aspect of the whole person.

General Guidelines for Talking about Disability

- Do not refer to a person’s disability unless it is relevant to the conversation
- Use “disability” rather than ‘handicap’ to refer to a person’s disability
- When referring to a person’s disability, use People First Language (such as “he has epilepsy”)
- Avoid negative or sensational descriptions of a person’s disability. Don’t say “suffers from, a victim of, or afflicted with.”

Examples of People First Language

Say:	Instead of:
People with disabilities	The handicapped or disabled
He/She uses a wheelchair	He’s/She’s wheelchair bound
Accessible parking, etc.	Handicapped parking, etc.
He/She needs or uses	He/She has a problem with

“The difference between the right word and almost the right word is the difference between lightning and the lightning bug.”

Mark Twain

Material developed by Illinois DHS

SECTION FIFTEEN

DDSN Policy

DDSN Policy on Human Rights Committee

Reference Number: 535-02-DD
Title Document: Human Rights Committee
Applicability: DDSN Autism Division; DDSN Regional Centers;
DSN Boards; and Contract Service Providers

Link to document:

[http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD\(Revised%20030309\).pdf](http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD(Revised%20030309).pdf)

Reference Number: 535-07-DD
Title Document: Obtaining Consent for Minors and Adults
Applicability: DDSN Regional Centers, DSN Boards and Contract
Service Providers

Link to document:

<http://ddsn.sc.gov/about/directivesstandards/Documents/currentdirectives/535-07-DD.pdf>

Reference Number: 535-12-DD
Title of Document: Advance Directives
Applicability: DSN Boards, Private Providers, DDSN Regional Centers

Link to document:

<http://ddsn.sc.gov/about/directivesstandards/Documents/currentdirectives/535-12-DD.pdf>

Reference Number: 600-05-DD
Title of Document: Behavior Support, Psychotropic Medications and
Prohibited Practices
Applicability: For Persons Receiving Services in: with Mental
Retardation, Community Day and Residential
Programs and Non-Residential Programs

All DDSN and Contracted Providers of Service
Coordination, Early Intervention, Residential and Day

Link to document:

[http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/600-05-DD%20\(Revised%20120110\).pdf](http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/600-05-DD%20(Revised%20120110).pdf)

Reference Number: 700-02-DD
Title Document: Compliance with Title VI of the Civil Rights Act of 1964, American's with Disabilities Act of 1990, Age Discrimination Act of 1975 and Section 504 of the Rehabilitation Act of 1973 and Establishment of a Complaint Process
Applicability: Central Office, Regional Centers, DSN Boards, and Contracted Service Providers

Link to document:

[http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/700-02-DD%20\(Revised%20070110\).pdf](http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/700-02-DD%20(Revised%20070110).pdf)

Reference Number: 603-07-DD
Title of Document: Do Not Resuscitate (DNR) Operational Guideline
Applicability: SCDDSN Regional Center Patients

Link to document:

[http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/603-07-DD%20\(Revised%20080110\).pdf](http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/603-07-DD%20(Revised%20080110).pdf)

Reference Number: 535-08-DD
Title of Document: Concerns of People Who Receive Services: Reporting and Resolution
Applicability: Central Office, Regional Centers, DSN Boards and Contracted Service Providers

Link to Document:

<http://ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-08-DD.pdf>

SECTION SIXTEEN

Scenarios for Discussion

Material developed by Illinois DHS

Scenarios for Discussion

1. Lori is receiving both residential and day services at the agency where she lives. Every morning, Monday through Friday, a bus stops at her house to take her and two other individuals to a day program, which is not very far from their home. In recent months Lori has become steadily more reluctant to get on the bus, although, once aboard, she seems fine. In the past two weeks she has had what appear to be panic attacks at the sight of the bus. Male staff are now being detailed to the home in the morning to physically carry her onto the bus. Lori seems to regard food as a very powerful reinforcer. In order to lessen the risks involved in the current staff response, it is proposed that her breakfast be withheld and served to her on the bus. Lori seems to regard food as a very powerful reinforcer. Additionally, the doctor has recommended Zoloft for her anxiety.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

2. Susan has been receiving services from public and private agencies for most of her life. In recent years her health has begun to fail and her doctor has diagnosed the early stages of congestive heart failure. It is essential, he says, that Susan quit smoking or risk major, and potentially fatal, medical complications. Susan has agreed many times to stop smoking, usually after having what she describes as her “last cigarette” as she is leaving for her part-time job answering the phone at the day program site. Although she has agreed to leave her cigarettes behind at home, by early afternoon she begins to demand a cigarette. If none are forthcoming, she becomes increasingly aggressive verbally and on two occasions has hurled herself from her wheelchair by saying that she wants to die. Staff, some of whom are ardent non-smokers, are quite worried about her health problems and are reluctant to contribute to them by helping her smoke. It is proposed that she be rationed to three cigarettes per day and that her house be declared a “non-smoking” area. That will mean that Susan will have to step outside to enjoy her smoke, a fact that may be sufficiently punishing to encourage her to cut down even more.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

3. Joe has been making life interesting for the third shift staff for some time since coming here from the SODC. He has developed a habit of urinating in appropriate places and seems to prefer using his and his roommate's dresser drawers. Adequate clean clothing for both Joe and his roommate is constantly in short supply. Both sets of parents regularly complain about Joe's actions and it was recently brought to the attention of the agency's Executive Director. Staff removed the dresser and locked it in the laundry room. Each evening after the roommates go to bed, staff takes out one outfit for each roommate and hang them in the closet. Staff report that the number of instances of inappropriate urination is nearly zero since the dresser was removed. It is proposed that the clothing remain inaccessible until such time that something better is figured out. Both guardians agree to the plan. Will you endorse this plan?

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

4. Jim is a fairly strong young man. He also seems to have experienced a life history in which he seldom was required to do anything he didn't want to do. Staff in his home often describe him, at least when their descriptions aren't unprintable, as "non-compliant." When demands are placed on him, he may become physically aggressive until the demands are eased. The doctor has prescribed Paxil for agitation, as well as to calm the physical aggression. The psychologist also recommends a behavior program in which his aggressiveness is ignored in hopes of extinguishing it. The BMC has approved this plan.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

5. Kate lives in a house with four other women of similar age and temperament. The level of activity in the house is often pretty intense and staff are kept busy trying to do their jobs while coping with the rivalries, which abound. Last week Kate walked out of the house following an argument with her roommate. Staff searched the area but were unable to find her. The local police brought her back unharmed about an hour later. It turned out that Kate had walked across the busy highway outside and then to a small strip mall about a mile away. The team is worried this might happen again and want some direction from the committee.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

6. Mary suffers from a degenerative muscle disease. She is experiencing more and more difficulty keeping her torso upright in her wheelchair. A physical therapist has recommended a "Posey vest" for use while in her wheelchair and the addition of bed rails to keep her in her bed at night.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

7. Donna is non-verbal, 25 years old and exhibits cyclical problem behavior. With the onset of her menstrual period she exhibits extreme self-injurious behavior to the extent that surgery was once required to repair the physical damage. Her mother, who is her guardian, is convinced that the problems will be alleviated by performing a hysterectomy, and she has convinced the family doctor to prescribe one. It is scheduled for next month. The team at the agency, however, is not so sure and comes to the committee for support in resisting the mother's demands.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

8. Chris is a generally pleasant young person who gets along well with others and is generally compliant with daily routines. However, at the day program, Chris has begun to occasionally run for the front door when demands are placed. Last week Chris left the area and ran across the highway a few blocks away. Eventually Chris was persuaded to return voluntarily. Issues of safety require that prompt action be taken. The team is recommending that a lock be installed on the front door, which can be activated by remote control when someone tries to "run." The door will otherwise remain unlocked.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

9. David has had a life-long history of self-injurious behavior. He hits himself repeatedly on the right side of his head when he is in "one of his moods." This typically happens in the evening when he is asked to do his share in cleaning up after dinner. The QSP analyzed the situation and found that he was involved in SIB on an average of 26 times per month around dinner clean-up times and one two times per month in other less-demanding situations. She concluded that the behavior was being controlled by attempts to escape what probably is an aversive task. She then developed a program in which staff will not lessen the clean-up demand, will block David's attempts to hit himself, and will reward him with verbal praise when he completes his job. They will reward him with popcorn every five minutes if his hands are in contact with dishes, utensils, or cleaning supplies at tabletop level, at which it is impossible to simultaneously hit himself.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

10. Jack is a healthy 35 year old who is extremely fond of Mountain Dew and Baby Ruth candy bars. Given any number of choices, Jack will exclusively choose this chocolate-and-caffeine laden combination. Anytime Jack has money in his pocket he is off to the corner store for his favorites. Jack's doctor has determined that Jack exceeds his ideal body weight (IBW) and needs to be put on a diet and lose 20 lbs to achieve his IBW. The doctor recommended a plan which includes no sweets and a significant increase in physical activity. Jack, who is his own guardian, is very opposed to the "no sweets" plan but thinks the increase in physical activity is good. He plans to get his bike out more often.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

11. Carol lives in a 3 bedroom, 2-bathroom group home with five women. Two issues are making life there difficult: phone and bathroom use. There is a constant bickering about who gets to use which, when, and for how long. Staff have imposed a ten minute phone call limitation, which the women don't like, but the constant arguing is more than anyone can stand. Staff developed a bathroom schedule which is, as staff put it, "etched in stone." Carol is attending the meeting representing her housemates and wants to know what can be done.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion (continued)

12. Juan is a 23 year old person with cerebral palsy who requires assistance in bathing. He dislikes taking showers or baths and usually has an offensive body odor most of the time. In the mornings, staff have attempted to persuade, coerce, trick and sometimes even bribe him with sweets to get him into the shower with a shower chair. The whole ordeal is unpleasant for everyone involved. Staff are looking for some answers because everything they have tried hasn't worked. Juan is a friendly person who loves to be with others, but others tend to shy away because of his lack of hygiene. Help!

Potential Rights Restriction

Related Issues to Explore

SECTION SEVENTEEN

Statement of Rights

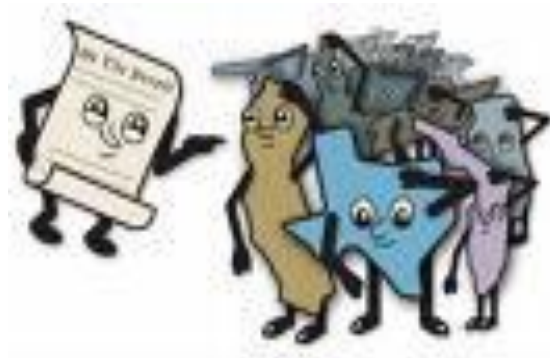
Declaration Of My Rights

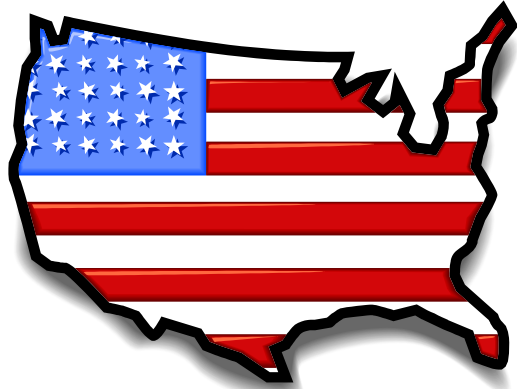
You have the same rights and responsibilities

guaranteed to all other Citizens



by the United States Constitution





And federal

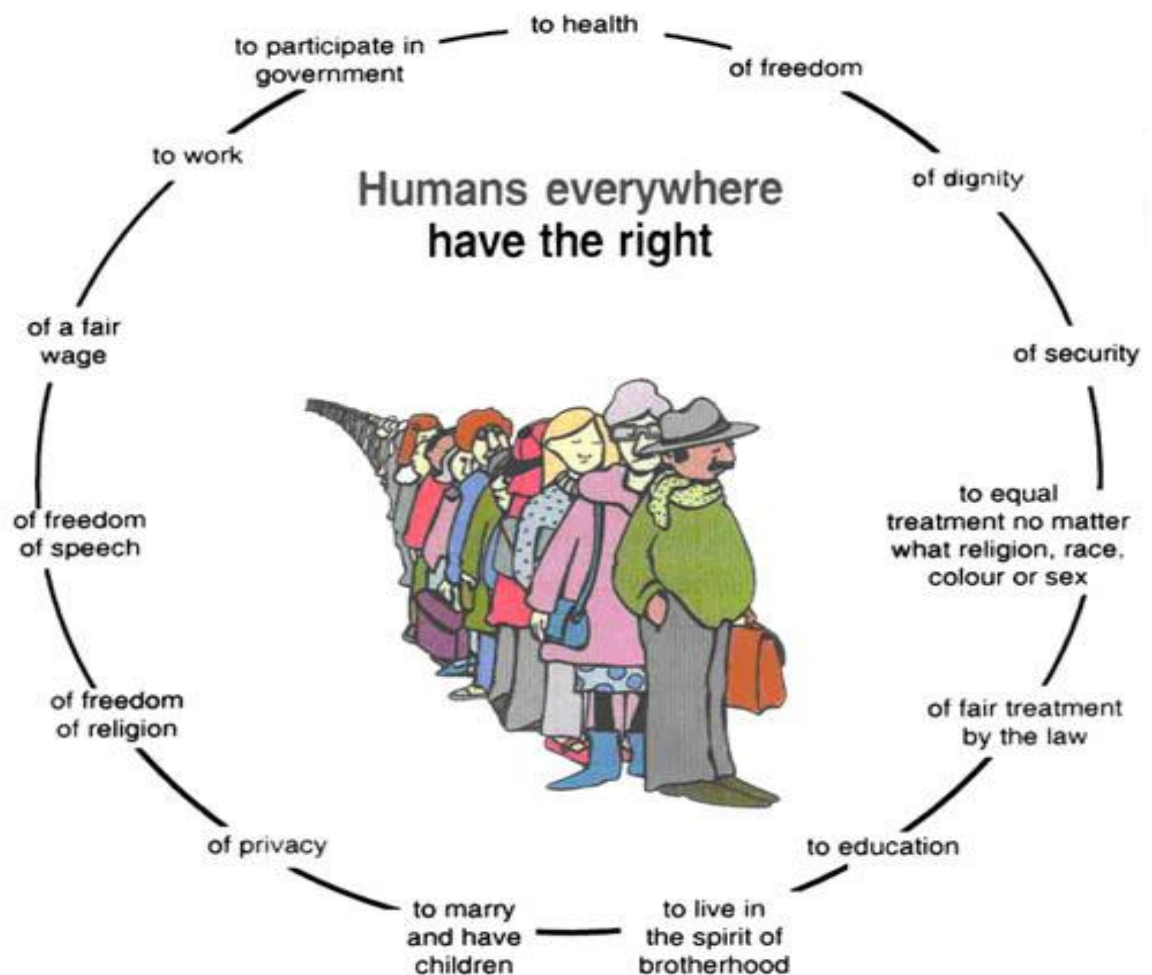


And state



Law

as well as the **Universal Declaration Of Human Rights** proclaimed by the United Nations.



These rights include, but are not limited to:

The right to be free from harm



The right to dignity and respect



The right to make choices



The right to be informed and attend any meetings about you



The right to receive and make phone calls



And send and receive Mail



The right to get a driver's license



The right to privacy



The right to prompt medical care and treatment



The right to go to the church of your choice



The right to socialize and participate in the Community



The right to physical exercise



The right to have a job and earn a fair wage



The right to handle your own money



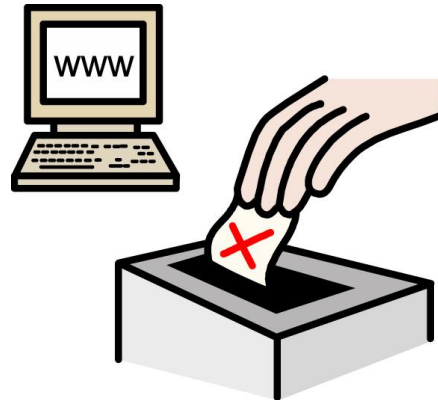
The right to get married



Or get a divorce



You have the right to vote



**You have the right to not be
discriminated against**



Resources: United Nations Universal Declaration of Human Rights; Constitution of the United States of America; Civil Rights Act of 1964; Americans with Disabilities Act (ADA); Fair Housing Act of 1963 amended in 1988; Health Insurance Portability and Accountability Act (HIPPA); Individuals with Disabilities Education Act (IDEA); Miranda Rights; Olmstead v. L.C. 1999; Rehabilitation Act of 1973; Fair Housing Act; New Freedom Initiative; South Carolina Code of Law; “All About Rights. A Guide to Supporting the Rights of People with Intellectual Disabilities”, CQL

I certify that the above rights were reviewed with me on this date

(Date)

by _____.
(Signature) (title)

(Person's signature)

(Date)

ADDITIONAL RESOURCES

Additional Resources

From: Council on Quality and Leadership

Quality in Practice: Human Rights Committee

http://www.thecouncil.org/QIP_HRC.aspx

Quality in Practice: Rights and Responsibilities

http://www.thecouncil.org/QIP_RightsandResponsibilities.aspx

Quality in Practice: End of Life Issues

http://www.thecouncil.org/QIP_EndofLifeIssues.aspx

Quiz on Rights: “Don’t Be Getting My Rights All Wrong”

http://www.thecouncil.org/uploadedFiles/Quiz_Rights.pdf

Other

Human Rights Resource Center

<http://www1.umn.edu/humanrts/edumat/>